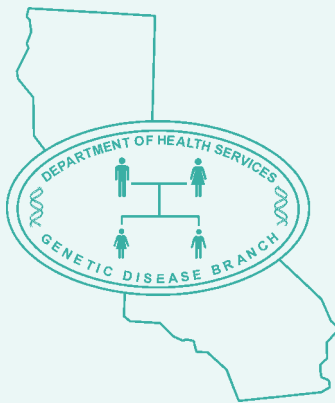


Choices in Prenatal Testing for Women 35 Years and Older

There is a different booklet for *women under 35* years old. These women should ask their doctor or clinic for the blue and white booklet called: **"The California Expanded AFP Screening Program."**

The California Expanded AFP Screening Program is voluntary. Women can refuse testing without losing insurance benefits, or eligibility or services from State programs.

California law prohibits the use of these test results by insurance companies or employers to discriminate against an individual. If you believe that you have experience discrimination as a result of participation write to George Cunningham, M.D., M.P.H., Chief, at the address below.



CALIFORNIA DEPARTMENT OF HEALTH SERVICES

Genetic Disease Branch

850 Marina Bay Parkway, F175

Richmond, CA 94804

866-718-7915 *toll free*

www.dhs.ca.gov/gdb

Choices in Prenatal Testing for Women 35 Years and Older

This booklet has information which will help pregnant women 35 years and older (at delivery) choose between:

❖ **diagnostic tests at a State-approved
Prenatal Diagnosis Center**

or

❖ **the Expanded AFP Screening Program
which includes a blood test—
and diagnostic tests if the blood test is positive.**

After reading this pamphlet, talk with a genetic counselor or your doctor about what is best for you.

Every pregnant woman wonders about the health of her fetus (unborn baby) and the possibility of birth defects. Women 35 and older may be especially concerned because certain birth defects (such as Down syndrome) are more common in the pregnancies of older women.

The three **prenatal tests** described in this booklet can detect **some** birth defects but **not all of them**. Down syndrome, open neural tube defects, abdominal wall defects, trisomy 18, Smith-Lemli-Opitz syndrome and other chromosomal defects are some of the birth defects found during testing. (These birth defects are described on pages 10 and 11.)

First, a woman needs to decide if she wants a screening test or a diagnostic test. A **diagnostic test** can tell whether or not the fetus **actually has** a certain birth defect. A **screening test** estimates the **chances (risk)** of the fetus having a certain birth defect. If the risk is high, a woman can then choose to have a diagnostic test.

The different tests are:

DIAGNOSTIC TESTS	SCREENING TEST
Amniocentesis Chorionic Villus Sampling (CVS)	Expanded AFP Blood Test

Who can help you make this decision?

Before deciding between a screening test and a diagnostic test, a woman who will be 35 years or older at delivery should talk to her doctor and/or genetic counselor. A genetic counselor can explain your choices in detail and answer any questions. Your doctor or clinic can refer you to a genetic counselor at a State-approved Prenatal Diagnosis Center.

Who else besides women age 35 and older should have genetic counseling?

- ◆ women with a medical or family history of inherited conditions
- ◆ women who know that the baby's father has a medical or family history of inherited conditions
- ◆ women who are taking certain medicines
- ◆ women who have insulin-dependent diabetes

PAYMENT FOR SERVICES

Some health plans (including Medi-Cal) may only cover certain prenatal tests and counseling services. Get information from your insurance company or health plan about your coverage. (See pages 12-13.)

Description of Diagnostic Tests

AMNIOCENTESIS

This test involves removing a small amount of the amniotic fluid that surrounds the fetus. It is usually done **between 15 and 20 weeks** of pregnancy. Sometimes it can be offered earlier or later than this.

First, an ultrasound picture locates the fetus and the fluid. Then a thin needle is inserted through the woman's abdomen to remove a small amount of the fluid from the uterus.

In the fluid are cells from the fetus. The chromosomes in these cells are examined for Down syndrome and other chromosomal defects. Also, the fluid can be tested for neural tube defects. (See pages 10-11.)

There is a small risk of miscarriage after amniocentesis: generally less than 1 in 100.

The results for these tests are available in about two weeks.

Amniocentesis is over 99% accurate in diagnosing Down syndrome and other chromosomal defects. Amniocentesis detects nearly all open neural tube defects.

The cost of these tests is about \$2,000 to \$3,200. The patient or her insurance is responsible for payment. The Expanded AFP Screening Program does not pay for amniocentesis unless authorized. (See pages 8-9.)

Diagnostic Tests

CVS (CHORIONIC VILLUS SAMPLING)

This test involves obtaining cells from the developing placenta instead of from the amniotic fluid. It is done early in pregnancy, **between 10 and 12 weeks**. An ultrasound picture locates the placenta in the uterus. A tiny piece of tissue is then removed from the placenta. This is done using a thin needle through the abdomen or a slender tube through the cervix. The cells from the placenta are examined for chromosomal defects.

There is a small risk of miscarriage: about 1 to 3 per 100. The final results are available in about two weeks. CVS is 98% accurate for the diagnosis of Down syndrome and other chromosomal defects. An AFP blood test is recommended at 15-20 weeks of pregnancy to screen for other defects.

The cost for CVS is about \$2,100 to \$3,500. The patient or her insurance is responsible for payment. The Expanded AFP Screening Program does not pay for CVS.

Description of the Screening Test

THE CALIFORNIA EXPANDED AFP SCREENING PROGRAM

For many years, the only prenatal tests for birth defects in women 35 years and older were amniocentesis and CVS. There is another choice, as well: the **Expanded AFP blood test**.

This blood test result is combined with a woman's age to calculate her own personal risk for having a fetus with Down syndrome or trisomy 18 in this pregnancy. **Knowing this risk can help a woman decide whether to have amniocentesis.** The blood test result also provides information about the risk of open neural tube defects, abdominal wall defects, and Smith-Lemli-Opitz syndrome.

Each pregnancy has its own risks, so results from previous tests do not apply to this pregnancy.

If the result is "screen positive," diagnostic follow-up tests are provided at no additional cost. (See pages 8-9.)

If the Expanded AFP blood test is "**screen negative**," the Program does **not** pay for any follow-up diagnostic tests.

What does the blood screening test involve?

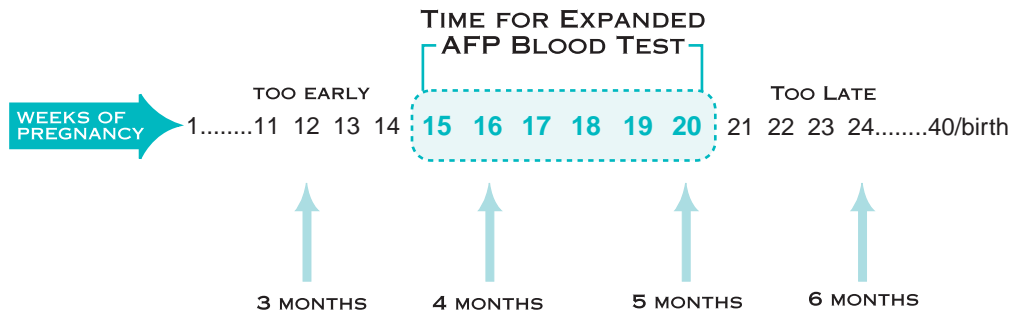
A small amount of blood is taken from the pregnant woman's arm. Her blood is tested for the amount of **AFP** (alpha-fetoprotein), **HCG** (human chorionic gonadotropin), and **UE** (unconjugated estriol). These substances are made by the mother's placenta and the fetus. At each week of pregnancy there are different amounts of these substances in the mother's blood. (What she eats does not affect these substances.)



When is the blood screening test done?

The blood test can only be done reliably **between 15 and 20 weeks of pregnancy**. *The best time is 16 to 17 weeks.* It is important to know how far along the pregnancy is. Ultrasound is very useful for this purpose.

The result of the blood test is sent to the patient's doctor or clinic within 1-2 weeks.



What does a “screen negative” result mean?

It means that the risk for *certain* birth defects is low enough that the Program does not consider follow-up tests necessary. The risk is calculated by measuring the amounts of AFP, HCG and UE in the woman’s blood and also by considering her age.

Since the blood test is just a screening test, *there is still a chance that the fetus may have a problem* — even when the test result is “screen negative.”

A “screen negative” result is the most common result.

About 9 out of 10 women tested will have a “screen negative” result.

- Because the risk for Down syndrome varies with a woman’s age, so does the chance of a “screen negative” result. For example, among 35 year old women, about 9 out of 10 will have a “screen negative” result for Down syndrome. Among 40 year old women, about 6 out of 10 will have a “screen negative” result.
- About 98 out of 100 women of all ages will have a “screen negative” result for neural tube defects and abdominal wall defects.
- About 99 out of 100 women of all ages will have a “screen negative” result for trisomy 18. The same is true for Smith-Lemli-Opitz syndrome.

(See pages 10-11 for information about these birth defects.)

What does a “screen positive” result mean?

It means that the risk for certain birth defects in this pregnancy is higher than usual (including Down syndrome, neural tube defects, abdominal wall defects, trisomy 18, and Smith-Lemli-Opitz syndrome). The risk is calculated using the amounts of AFP, HCG and UE found in the woman’s blood. Her age is part of the calculation for the risk of Down syndrome and trisomy 18.

Most of the time, however, the reason for the result is **not** a birth defect. The **most common reasons** for a “screen positive” result include:

- ◆ the due date is earlier or later than thought, *or*
- ◆ there is more than one fetus (twins, triplets), *or*
- ◆ the substances in the blood varied more than usual, without any known pregnancy problem.

To determine the reason for the “screen positive” result, **genetic counseling and follow-up diagnostic tests are offered** and paid for by the Program. Since receiving this result may cause anxiety, it is important to remember that *most women with “screen positive” results will have normal follow-up tests and healthy babies.*

SUMMARY OF TEST RESULTS

“screen negative” →	No follow-up tests are offered by the Program.
“screen positive” →	Follow-up tests are provided at no extra cost at a State-approved Prenatal Diagnosis Center.

If the test is “screen positive,” what happens then?

A woman with a “screen positive” result will be **called by her doctor or clinic**. She will be offered diagnostic services at a **State-approved Prenatal Diagnosis Center**. When authorized, these are the follow-up services covered by the Program:

- **Genetic counseling** - A professional counselor discusses the pregnancy and family medical history. Questions are answered to help the woman make decisions about further testing.
- **Ultrasound** - A picture of the fetus is made using sound waves. This picture shows the age of the fetus and whether there are twins. The detailed ultrasound done at a Prenatal Diagnosis Center can also detect certain birth defects.
- **Amniocentesis** - A small amount of fluid is taken out of the uterus by experienced, State-approved doctors. The fluid and the fetal cells in it are tested for specific birth defects.

Women may refuse any of these services at any time.

What if the follow-up tests show that the fetus has a birth defect?

Information will be given to the woman by a doctor or genetic counselor at the Prenatal Diagnosis Center. They will discuss the type of birth defect that has been found and any available treatments. They will also discuss options for continuing or ending the pregnancy. The woman can then make a decision.

The Expanded AFP Screening Program does not pay for any other medical services after the follow-up tests. Referrals for special support services are available.

Birth Defects Found by the Program

What birth defects may be found through follow-up testing?

Down syndrome, open neural tube defects, abdominal wall defects, trisomy 18, Smith-Lemli-Opitz syndrome and some other birth defects may be found.

Down Syndrome

Down syndrome is a common cause of mental retardation. Heart defects are often present, as well. Down syndrome can occur in the fetus of a woman of any age.

Down syndrome is caused by an extra chromosome #21. Chromosomes are packages of genetic material found in every cell of the body. Birth defects can occur when there are too few or too many chromosomes.

As women get older, their chances increase for carrying a fetus with Down syndrome.

For example, on average:

- ◆ 35 year old women have about 1 chance in 384 of having a child with Down syndrome.
- ◆ 40 year old women have about 1 chance in 112.

Not all cases of Down syndrome are found by the Program. In women 35 and older, about 87% of the cases of Down syndrome are detected.

★ **Important Note:** The screening test is never 100% successful in detecting Down syndrome pregnancies. Only the diagnostic tests described on pages 3 and 4 will find almost 100% of them.

Birth Defects Found by the Program

Neural Tube Defects (NTDs)

As a fetus is forming, the neural tube extends from the top of the head to the end of the spine. This becomes the baby's brain and spinal cord. The neural tube is completely formed by 5 weeks after conception.

An opening in the spine is called **spina bifida**. This defect often causes paralysis of the legs. It may also cause loss of bowel and bladder control. Frequently, there is water-on-the-brain (hydrocephaly) which requires surgery.

Anencephaly occurs when most of the brain does not develop. This defect causes the death of the fetus or newborn.



Abdominal Wall Defects

Fetuses with these defects have **abnormal openings** on the abdomen. Intestines and other organs are formed outside the body. Surgery after birth often corrects the defect.

Trisomy 18

Trisomy 18 is caused by an extra chromosome #18. Babies with trisomy 18 have severe mental retardation and physical defects. They usually die before birth or in early infancy.

Smith-Lemli-Opitz Syndrome

This is a very rare birth defect. Babies with Smith-Lemli-Opitz syndrome cannot make cholesterol normally. Babies need to make cholesterol, even before birth, to help their brains and bodies develop. Children born with this condition are mentally retarded and may have numerous physical defects.

Can the Expanded AFP Screening Program detect every type of birth defect?

No. There are birth defects which cannot be detected by Expanded AFP Screening. Even when the blood test is “screen negative,” there is still a chance the fetus may have a problem.

HOW MANY BIRTH DEFECTS ARE FOUND?

These birth defects **do not occur very often**. However, **if there is one of these birth defects**, the Expanded AFP Screening Program helps detect it. Among women who have the Expanded AFP blood test and follow-up tests, the Program finds about:

- 87% of the cases of Down syndrome in the pregnancies of women 35 years of age and older
- 97% of the cases of anencephaly
- 80% of the cases of open spina bifida
- 85% of the cases of abdominal wall defects
- 75% of the cases of trisomy 18 in the pregnancies of women 35 years of age and older
- 60% of the cases of Smith-Lemli-Opitz syndrome.

How much does the Expanded AFP Screening Program cost?

At this printing, the fee is **\$105**, but check with the doctor or clinic about the most current fee. The fee covers the blood test **and** authorized follow-up services at a State-approved Prenatal Diagnosis Center.

For women who already have had CVS (chorionic villus sampling) during this pregnancy, the current fee is \$57. These women only have testing for neural tube defects and abdominal wall defects.

The Program mails a bill and insurance form to women who have the blood test. Women with private insurance should complete the insurance form and return it.

Insurance companies and HMOs are required to pay for Expanded AFP testing, except employers who are self-insured.



Women with Medi-Cal usually do not receive a bill. If they do, they should return the bill with their Medi-Cal number. Women without insurance may make monthly payments and are responsible for the whole amount.

Any charges for drawing blood are not included in the program fee.

Each woman should consider her prenatal testing choices carefully.

- ◆ Women who decide to have the Expanded AFP blood test must sign the consent form at the end of this booklet and have blood drawn between 15 and 20 weeks.
- ◆ Women who decide to have amniocentesis or CVS, should make an appointment at a State-approved Prenatal Diagnosis Center.
- ◆ Women should see a genetic counselor if they need help deciding between a screening test and diagnostic tests.
- ◆ Women can decide to have no prenatal testing.

Each woman should check with her insurance company or prepaid health plan about payment for these choices.

Summary of Prenatal Testing Choices

	Test	When Done	Description	Cost	
Screening Test	CVS	10-12 weeks of pregnancy	<ul style="list-style-type: none"> • Diagnoses 98% of Down syndrome and other chromosomal defects • Not a test for neural tube defects, so an AFP blood test is recommended at 15-20 weeks • Chance of miscarriage is about 1%-3% 	Approx. \$2,100 to \$3,500 plus \$57 for AFP blood test	Diagnostic Tests
	Amniocentesis	<i>usually at</i> 15-20 weeks of pregnancy	<ul style="list-style-type: none"> • Diagnoses 99% of Down syndrome and other chromosomal defects • Also diagnoses most open neural tube defects, abdominal wall defects, and some other birth defects • Chance of miscarriage is less than 1% 	Approx. \$2,000 to \$3,200	
	Expanded AFP Screening Program	15-20 weeks of pregnancy	<ul style="list-style-type: none"> • Estimates a woman's chance of having a fetus with Down syndrome or trisomy 18 • Also detects most open neural tube defects and abdominal wall defects, as well as some cases of Smith-Lemli-Opitz syndrome. • If the result is "screen positive," the Program pays for amniocentesis at a State-approved Prenatal Diagnosis Center. • Predicts about 87% of fetuses with Down syndrome in women 35 and older. Will miss detecting some Down syndrome and other chromosomal defects. 	\$105	

CLINICIAN'S COPY
(Remove and file in patient's chart.)

Patient's name _____
(PLEASE PRINT)

ID# _____

CONSENT/REFUSAL

FOR THE CALIFORNIA EXPANDED AFP SCREENING PROGRAM

1. I have read the information about the **California Expanded AFP Screening Program** which is contained in this booklet (or have had it read to me by _____).
2. I have been informed that:
 - a) the purpose of the California Expanded AFP Screening Program is to detect most fetuses with Down syndrome, open neural tube defects, abdominal wall defects, trisomy 18, and Smith-Lemli-Opitz syndrome. However, not all such defects can be detected by the Program.
 - b) there are other birth defects that cannot be detected by this Program.
 - c) if the result is "screen positive," I will need to make a decision regarding follow-up testing. Authorized follow-up tests are covered by the Program and will be discussed with me in more detail.
 - d) if the result is "screen negative," the Program will not pay for any follow-up testing.
 - e) if the fetus is found to have a birth defect, the decision to continue or terminate the pregnancy will be entirely mine.
 - f) participation in the California Expanded AFP Screening Program is voluntary. I can refuse any tests at any time.



(over)

3. I have read the detection rates for certain birth defects as they are described in this booklet.
4. I have been informed that a blood specimen for the California Expanded AFP Screening Program is only reliable between 15 and 20 weeks of pregnancy.
5. I have been informed about the option of having CVS or amniocentesis instead of the Expanded AFP blood test.
6. I have had my questions answered to my satisfaction.

YES	I request that blood be drawn for the Expanded AFP Screening Program. Signed _____ Date _____ I should have my blood drawn between _____ and _____ month day year month day year
No	I request that blood not be drawn for the Expanded AFP Screening Program. Instead, I have chosen _____ Signed _____ Date _____

TEAR HERE AND FILE IN PATIENT'S CHART

I understand that the blood specimen and information obtained during the testing process become the property of the California Department of Health Services. They may be used for program evaluation or research by the Department or Department-approved scientific researchers without identifying the person or persons from whom these results were obtained, unless I specifically prohibit such use in writing. All information procured by the Department of Health Services, or by any other person, agency or organization acting jointly with the Department in connection with such special studies, shall be confidential. I may obtain additional information about the study or prohibit the use of my specimen by writing George Cunningham, MD, MPH, Genetic Disease Branch, 850 Marina Bary Parkway, F175, Richmond, CA 94804.

If new information becomes available about a birth defect detected during this pregnancy, the information may be sent to me unless I specifically prohibit it by writing to George Cunningham, MD, MPH at the above address.

PATIENT'S COPY

Patient's name _____
(PLEASE PRINT)

ID# _____

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 - d) if the result is "screen negative," the Program will not pay for any follow-up testing.
 - e) if the fetus is found to have a birth defect, the decision to continue or terminate the pregnancy will be entirely mine.
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YES	I request that blood be drawn for the Expanded AFP Screening Program. Signed _____ Date _____ I should have my blood drawn between _____ month day year and _____ month day year
No	I request that blood not be drawn for the Expanded AFP Screening Program. Instead, I have chosen _____ Signed _____ Date _____

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If new information becomes available about a birth defect detected during this pregnancy, the information may be sent to me unless I specifically prohibit it by writing to George Cunningham, MD, MPH at the above address.

NOTICE OF INFORMATION PRACTICES AND PRIVACY PRACTICES CALIFORNIA DEPARTMENT OF HEALTH SERVICES
GENETIC DISEASE BRANCH PRENATAL SCREENING PROGRAM - EFFECTIVE DATE APRIL 14, 2003

THIS NOTICE DESCRIBES HOW PERSONAL (INCLUDING MEDICAL) INFORMATION ABOUT YOU OR YOUR NEWBORN MAY BE USED AND DISCLOSED AND HOW YOU CAN GET ACCESS TO THIS INFORMATION. PLEASE REVIEW IT CAREFULLY.

Department's Legal Duty. Federal and State laws restrict the use, maintenance and disclosure of personal (including medical) information obtained by a State agency, and require certain notices to individuals whose information is maintained. State laws include the California Information Practices Act (Civil Code 1798 et. seq.), Government Code Section 11015.5 and Health and Safety Code Section 124980. The federal law is the Health Insurance Portability and Accountability Act of 1996 (HIPAA) 42 USC 1320d-2(a)(2), and its regulations in Title 45 Code of Federal Regulations Section 160.100 et. seq. In compliance with these laws, you and those providing information are notified of the following:

Department Authority and Purpose for the Prenatal Screening Program. The Department of Health Services collects personal and medical information as permitted in Health and Safety Code Sections 124997, 124980, 125000, 125050, 125055, 123055. The information is collected and used according to procedures in State regulations (17 CCR 6527, 6529, 6531 and 6532). It is used to estimate the risk of serious birth defects in the pregnancy and provide diagnostic testing for the pregnant women. If not provided, problems could result such as not detecting an affected fetus, falsely reporting increased risk causing unnecessary invasive testing, or not being able to bill properly for the services provided. This information is collected electronically and includes such things as your name, address, testing results, and medical care given to you.

Uses and Disclosure of Health Information. The Department of Health Services uses health information about you or your newborn for screening, to provide health care services, to obtain payment for screening, for administrative purposes, and to evaluate the quality of care that you or your newborn receive. Some of this information is retained for as long as 21 years. The information will not be sold.

The law also allows the Department to use or give out information we have about you or your newborns for the following reasons:

- For research studies that have been approved by an institutional review board and meet all federal and state privacy law requirements, such as research related to preventing disease.
- For medical research without identification of the person from whom the information was obtained, unless you specifically request in writing that your information not be used by contacting the person listed below.
- To organizations, which help us in our operations, such as by collecting fees. If we do, we will make sure that they protect the privacy of information we share with them as required by federal and state law.

The information is otherwise confidential and will not be released without your written authorization. If you choose to sign an authorization to disclose information you can later revoke that authorization to stop any future uses and disclosures by contacting the person listed below.

The Department may change its policies at any time subject to applicable laws and regulations. If it does so, we will notify you and you may request a copy of our current policies or obtain more information about our privacy practices, by contacting the person listed below or consulting our website at www.dhs.ca.gov/pcfh/gdb. You may also request a paper copy of this Notice.

Individual Rights and Access to Information. You have the right to look at or receive a copy of your or your newborn's health information. If you request copies, we will charge you \$0.10 (10 cents) for each page. You also have the right to receive a list of instances where we have disclosed health information about you or your newborn for reasons other than screening, payment or related administrative purposes. If you believe that information in your or your newborn's record is incorrect or if important information is missing, you have the right to request that we correct the existing information or add the missing information. You have the right to ask us to contact you at a different address, post office or telephone number. We will accept reasonable requests.

You may request in writing that we restrict disclosure of your or your newborn's information for health care treatment, payment and administrative purposes. We may not be able to agree to your request.

Complaints. If you believe that we have not protected your or your newborn's privacy or have violated any of your or your newborn's rights and wish to complain, please call or write us at: Privacy Officer, CA Department of Health Services, P.O. Box 942732, Sacramento, CA 94234-7320, (916) 255-5259 or (877) 735-2929 TTY/TDD/

You may file a complaint by calling or writing the **Privacy Officer**, CA Department of Health Services, at the address and telephone number above. You may also contact the Secretary of the Department of Health and Human Services, Office for Civil Rights at 50 United Nations Plaza, Room 322, San Francisco, CA, 94102, telephone (800) 368-1019. Or you may call the U.S. Office of Civil Rights at 866-OCR-PRIV (866-627-7748) or 866-788-4989 TTY.

The Department cannot take away your health care benefits or do anything to hurt you in any way if you choose to file a complaint or use any of the privacy rights in this Notice.

Department Contact – Who Maintains the Information. The information on this form is maintained by the Department of Health Services, Genetic Disease Branch. The Chief of the Genetic Disease Branch is George Cunningham, M.D., 850 Marina Bay Parkway, Richmond, California, 94804, (510) 412-1499. He is responsible for the system of records and shall, upon request, inform you about the location of your records and respond to any requests you may have about information in those records.

AMERICANS WITH DISABILITIES ACT - Notice and Information Access Statement

Policy of Nondiscrimination on the Basis of Disability and Equal Employment Opportunity Statement

The Department of Health Services, State of California does not discriminate on the basis of disability in employment or in the admission and access to its programs or activities.

The Deputy Director, Office of Civil Rights, 714 P Street, Room 1050, Sacramento, CA 95814 has been designated to coordinate and carry out the agency's compliance with the nondiscrimination requirements of Title II of the Americans with Disabilities Act (ADA). Information concerning the provisions of the ADA, and the rights provided thereunder, are available from the ADA Coordinator.

CALIFORNIA DEPARTMENT OF HEALTH SERVICES

Genetic Disease Branch

850 Marina Bay Parkway, F175

Richmond, CA 94804

866-718-7915 *toll free*

www.dhs.ca.gov/gdb

August 2003